

**KENTUCKY COMMISSION
ON
SERVICES AND SUPPORTS
FOR INDIVIDUALS WITH INTELLECTUAL
AND OTHER DEVELOPMENTAL DISABILITIES**

**September 13, 2012
Fair Oaks, 4th Floor
Frankfort, Kentucky**

MEMBERS PRESENT

Commissioner Stephen Hall	Harold Kleinert
Deputy Secretary Eric Friedlander	
Deputy Commissioner Betsy Dunnigan	
Deputy Commissioner Reina Diaz-Dempsey for Commissioner Lawrence Kissner	
Pat Seybold	William Shaw
Cathy Edwards	
Shanon McCracken for Clyde Lang	Steve Zaricki
Patty Dempsey	Gwynn Royster
Cherri Lolley	Steve Shannon
David Matheis for David Beach	Anne Montgomery

MEMBERS ABSENT

Linda Sandidge	Representative Carl Rollins
Senator Tom Buford	Representative Jimmie Lee
Malkanthie McCormick, M.D.	Glenna Taylor
Senator Julie Denton	

OPENING REMARKS

Commissioner Hall opened the meeting by thanking the members of the Commission for their attendance and participation.

REVIEW OF MINUTES

The minutes of the meeting were approved with no changes.

COMMITTEE REPORTS

Participant Direction:

On Thursday, September 13, 2012 before the HB 144 meeting this group met. The Participant Directed committee opened up with Cathy Edwards relaying her disappointment with the transportation system. This group also commented on the use of a webinar as a tool for communication. Cathy Edwards commented that if you are on the phone listening to the webinar and would like to have or view copy; the copy would not have volume of the meeting due to

recording. Anne Montgomery and Marie Allison have been added to this group and the committee would like to schedule awareness events around the state.

Community Integration:

On Thursday evening, September 7, 2012 members of the HB144 Community Integration Committee met with 11 individuals at the Four Rivers Regional offices in Paducah, KY. The purpose of the meeting was to gather feedback from individuals, advocates and providers in this region of the state regarding their perceptions of community integration and the barriers that they see and experience in maximizing the potential for full inclusion in the community. The meeting participation was lively and despite a brief interruption for a tornado warning, the meeting lasted about two and one-half hours.

Participants were largely providers of services supporting individuals in a variety of settings throughout the region. They spoke passionately about those they serve and their efforts in integrating those individuals into community activities, functions, and employment, volunteerism and family activities. There was a self-advocate and a family member in attendance. The advocate spoke of her fondness for her 'day program; She had friends and a routine that she liked. The next meeting will be in Ashland/Prestonsburg.

Health and Wellness:

1) This committee met on August 29th 1:00 – 2:30 in the 4th Floor DBHDID, Small Conference Room. **UPDATES:**

- a) Harold and Kathy made presentations with Chas Moseley on using state data to inform policy in Kentucky. Presentations made at the State of the Science and Re-Inventing Quality Conferences. Also Kathy is talking with Director for Center for Developmental Disability Evaluation & Research (CDDER) at UMass about exploring feasibility of using state level data for the purpose of health surveillance.
- b) HDI was involved in drafting Healthy Kentucky 2020 disability chapter (not yet available)
- c) HDI funded 8 mini grants funded health and wellness projects around the state (results being written up now) with participant organizations including SCL provider, parks and rec dept., and county public health dept.

2) CURRENT ACTIVITIES: Health and Wellness

Webinar for 210 SCL providers on 8/16 to announce “Health Messages” pilot project for up to 25 organizations. Collaboration with University of Illinois at Chicago’s RRTC on Aging and Developmental Disabilities (flier and application attached). This 12 week program led by an individual receiving supports teamed with a direct support professional will launch at the end of Oct. Results will be used to refine activities prior to a statewide SCL launch in the

spring. Applications are due in September. Already, we are being asking if Michelle P can participate. We are keeping narrower focus for pilot.

Challenges to Sustained Efforts in Health Wellness (HDI perspective): All efforts are data driven, but rely heavily on time that is not dedicated solely to this effort (i.e., free training, materials and TA from Illinois RRTC, DDID staff TA time, HDI coordination from RA and Training Director). To truly achieve lasting change, we must find funds for a dedicated health and wellness professional to provide ongoing supports.

PROPORTION OF PEOPLE WHO ENGAGE IN MODERATE PHYSICAL ACTIVITY FOR AT LEAST 30 MINUTES 3 TIMES A WEEK

	Overall in State	N	Institutional	Comm-Based	Individ's Home	Parent's Home
KY	21%	411	32%	18%	28%	25%
NCI Average	26%	7,753	18%	26%	29%	28%

KY 2008 SCL Data: 12.2% KY Community-Based Current: 18%

3) NEXT STEPS: Health and Wellness

4) CURRENT DATA: Psychotropic Medications KY and National 2010-11 psychotropic meds data:

	Overall In State	N	In Institution	In Community-Based	In Individual Home	In Parent's Home
KY (within average range of NCI states)	55%	465	36%	67%	49%	40%
NCI	54%	8390	53%	68%	53%	36%

KY 2008 SCL data: 71.4% KY Community-Based Current 67%

5) CURRENT ACTIVITIES and NEXT STEPS: Medications

6) OTHER HEALTH INDICATORS – KY IS “IN RANGE” For Health Care Indicators, and Actually Above Average for Vision and Hearing Screenings

REPORT TO HB 144 COMMISSION (September 13)

COMMUNITY BELONGING INITIATIVE

DDID facilitated the kick off to this initiative with two, 1-day training sessions held on 9/19 at Kenlake and 9/20 at Jenny Wiley State Park by Dr. Angela Amado. Over 50 people and 13 providers were selected to participate. The next step is a bi-monthly follow-up contact with each agency by Dr. Amado via phone or webinar. In late January, Dr. Amado will have face-to face contact with each participant and their person centered team to discuss progress and how to address barriers to community inclusion. The initiative continues in this same rotation of face to face and phone or webinar follow-ups until Spring of 2013. At the end of the project she will return to meet with the large groups again to provide strategies for sustainability and to assist the providers in serving as model agencies in their respective regions of the state.

Dr. Amado currently serves as a Research Associate at the Institute on Community Integration, University of Minnesota where she supervises and coordinates various training and research projects concerning community inclusion of persons with intellectual/developmental and other disabilities, community bridge-building, person-centered planning, Person-Centered Agency Design, and self-determination. She is also the Executive Director of the Human Services Research and Development Center where she provides training, consulting, and systems change in person-centered initiatives. Dr. Amado began her career as a Teacher in 1973 for children labeled severely emotionally disturbed and “borderline psychotic” in California and has served in a variety of positions including higher education since that time in both the United States and Canada. She has numerous publications and awards for her work and recently served as the Chair of the Association President’s Inclusion Task Force for the American Association on Intellectual and Developmental Disabilities.

REVIEW OF ANNUAL REPORT

Eric Freeland reported that a copy of the draft HB 144 Annual Report was in the packet. He asked that HB 144 Members to review and send recommendations for revisions to Jennifer O’Brien by October 1, 2012. **UPDATES**

HUMAN DEVELOPMENT INSTITUTE:

This group is working closely with the KY Division of Developmental and Intellectual Disabilities on the Health Messages Pilot. In collaboration with DDID, we conducted a Webinar for 210 SCL providers on 8/16 to announce the Health Messages pilot project for up to 25 organizations. We are collaborating with the University of Illinois at Chicago’s RRTC on Aging and Developmental Disabilities in this initiative. This 12 week program - led by an individual receiving supports teamed with a direct support professional - will launch at the end of October. Results will be used to refine activities prior to a statewide SCL launch in the spring. Applications were due this month.

KY COUNCIL ON DISABILITIES:

The Council continues to fund ‘The Future is Now’, a project to assist families in planning for the future. This project brings together families (six-ten) to attend a five part series to discuss and plan for the future. These sessions provide families with working documents, presenters on a variety of topics to discuss life planning and goals. The Future is now has been offered statewide and has been extremely successful.

1. Emergency Management – The Council along with several partners will host an Inclusive Preparedness conference in Western Kentucky at the end of the month. This conference will be similar to the one held in Eastern Kentucky last year, which was a huge success.
2. KySAFF – The Council continues to fund Kentucky Self-Advocates for Freedom. There are currently 9 chapters throughout the state with several hundred members. All local chapters are very active within their communities. Statewide initiatives are administered through a board of directors comprised of representatives from all local chapters.
3. Recreation Involvement Fund – This program offers opportunities for individuals to join local gyms, recreational facilities, and to participate **in inclusive activities** to improve health and wellness. There are currently over 100 individuals participating in the program. The stories of weight loss, friendships, improved balance and mobility and self-confidence have demonstrated the success of the program.
4. The Council is currently working on the development of projects in the area of health, education and employment.
5. The Council voted at their August meeting to suspend the Consumer Involvement Fund, a program that offered financial support for individuals with developmental disabilities and their families to attend conference and trainings. The program will be undergoing an evaluation over the next year. This has not occurred in several years and it was deemed necessary by the Council to ensure that intended outcomes are measurable.
6. SCL regs – Council staff have completed a comparison of the old regulation and the proposed regulations. The Council is monitoring all comments and input, with plans to attend and present at the Public Hearing on September 21.
7. Restraint & Seclusion regulations –The Council is collaborating with Protection & Advocacy to educate legislators, administrators, teachers and parents about the potential impact of proposed regulations on this issue. The regulations would limit the use of restraint and seclusion in school. The collaborating partners are supportive of the majority of the proposed changes as the changes reflect the current national data that supports the use of alternatives to restraint and seclusion such as positive behavioral supports. The Council will be making comments at the public hearing on September 25th.
8. Adult abuse registry – The Council has been and will continue to be proactive in the pursuit of implementation of an Adult Abuse Registry in Kentucky. It is known that the funding has been appropriated and thus there is a need to implement this positive protection. The Council will continue to work with their collaborative partners and the Cabinet to move the registry forward.
9. Medication dispensing in ICF/DD facilities – There appears to be some confusion about the ability of DSP’s to dispense medications in facilities. The Council has been working with the Wendell/Foster Center to receive clarification on this regulation. The Council’s interest stems from our belief that all individuals should be active in their communities. That can be difficult, If residents must return to a facility at certain times to take

medications. The regulations do indicate that unlicensed staff can administer medications with training however it is not clear what ‘training’ is referenced. The Council and Wendell/Foster are working with the Board of Nursing, BHDID and OIG to obtain clarification.

PROTECTION and ADVOCACY:

Personal Care Homes (PCHs)

On August 14, 2012, Protection & Advocacy released an Investigative Report of Golden Years Rest Home in Jenkins, Kentucky. The report provided an example of how one personal care home in Kentucky failed to protect and adequately meet the needs of our citizens with mental health diagnoses and with intellectual and developmental disabilities. Observations about the response of the system responsible for providing oversight of licensed PCHs in Kentucky were also included in the report. The twenty-one page report concluded that the closure of Golden Years Rest Home does not address or change the current service system in place in Kentucky, a system that does not effectively and appropriately support persons with mental illness. There was media coverage of the report from various outlets. Later this month, P&A will meet with Audrey Haynes, Secretary of the Cabinet for Health and Family Services (CHFS), and others regarding the continued use of state dollars to serve persons with mental illness in congregate and segregate settings in Kentucky. The United States Supreme Court held in *Olmstead v. L.C.* that unjustified segregation of persons with disabilities constitutes discrimination in violation of Title II of the Americans with Disabilities Act (ADA).

Regulation of the use of Restraint/Seclusion in Schools

P&A continues to meet with the Kentucky Department of Education (KDE) regarding a regulation

for the use of Restraint and Seclusion in schools in Kentucky. P&A attended and arranged for two parents of children who had been restrained at school to provide public comments at the August meeting of the Kentucky Board of Education who voted for passage of the regulation at that meeting. The KDE has since filed the regulation with LRC. Parents of children who have been restrained or secluded at school and P&A will attend and provide comments at the public hearing scheduled for later this month and will also submit written comments to the KDE.

Kentucky Protection & Advocacy and the Commonwealth Council on Developmental Disabilities continues to gather information about the use of restraint and seclusion in schools and recently developed and posted the below referenced survey. Link for survey can be found at <https://www.surveymonkey.com/s/78SKHSW>.

Voting Event held

The passage of the ADA in 1990 paved the way for other civil rights laws, including the Help America Vote Act (HAVA) of 2002. This year marks the 10th anniversary of the passage of HAVA. This landmark event outlined improvements to voting standards, including improving accessibility to the voting process for individuals with disabilities. In celebration of the 10th anniversary of the passage of HAVA P&A held “Accessing Your Power: a Celebration the ADA and Your Voting Rights” event on Wednesday, August 22, 2012, at the Griffin Gate Marriott in Lexington. The more than eighty attendees heard from the Secretary of State Alison L Grimes, the state ADA coordinator for Kentucky, and a panel of self-advocates who shared their personal stories about accessibility and voting. Attendees were also provided with information about

restoration of voting rights for individuals with disabilities and utilization of on-site voter registration.

Protection & Advocacy for Individuals with Developmental Disabilities (PADD) Advisory Board

The Protection & Advocacy for Individuals with Developmental Disabilities (PADD) Advisory Board will provide information about regulatory changes to the SCL and Michelle P Waivers to recipients of these waiver services. The PADD Advisory Board is a seventeen (17) member board comprised of Kentuckians with developmental disabilities and their family members.

“Knowledge is Power” Conference held

Members of the Protection & Advocacy for Individuals with Mental Illness (PAIMI) Advisory Council, with technical assistance provided by P&A staff, hosted the “Knowledge is Power” Conference on 8/2/12 at the Northern Kentucky Convention Center in Covington, Kentucky. More than seventy persons attended the conference, including those living in Kentucky and individuals from other states, including Florida, Arizona, West Virginia, and Ohio. The subject matter of workshops included the topics of bullying, guardianship, including restoration of rights, voting, and self-advocacy. Additionally members of the Protection & Advocacy for Individuals with Developmental Disabilities (PADD) Advisory Board presented on the cemetery restoration project of Frankfort State Hospital and School, at the conference.

Civil Rights Symposium

P&A staff recently attended the Civil Rights Symposium held in Lexington by the U.S. Department of Justice, Community Relations Service - Southeast Region IV, Atlanta, GA, and had the opportunity to hear from and meet with Assistant U.S. Attorney General Tom Perez.

MEDICAID UPDATES

The following statistics were reported.

Money Follows the Person/Kentucky Transitions:

- Updated Numbers as of September 10, 2012
 - Total transitions since the beginning of the program: 375
 - Elderly: 99
 - Physically Disabled: 88
 - Brain Injury: 48
 - IDD: 140
 - 197 currently in the transition process
 - 891 ineligible or declined (failed to meet eligibility criteria, care needs exceed services available in the community, individual or guardian changed their mind, health needs changed).

Waiver Submissions:

- SCL Waiver- Amendment to add slots approved for funding in the 2012-14 biennium budget submitted September 5, 2012.

Active Waiver Members:

As of September 1, 2012

- ABI Acute-183
- ABI Long Term Care- 223 (includes MFP members who have transitioned to this waiver)
- HCB-9,668
- Model II Waiver-52
- Michelle P-7,457
- SCL- 3,709

PUBLIC COMMENTS

September 20, 2012 a Broadway Production entitled “Handicap This” will perform at River Park Center